

Participant Information and Consent Form for online survey & physical function

Research Project Title: danceSing Care Evaluation NICR 3735

Background, aims of project

You are invited to participate in a web-based online survey and some physical assessments on the impact of the danceSing Care programme on social contact, health and wellbeing.

The danceSing Care programme involves 2-3 music or music and movement classes per week in your care home. We will be running two groups. The first group (intervention group) will start the programme straight away. The second group is called a waitlist control group; they will complete the same assessments at the same time as the first group, but will only start the programme 12 weeks later. We will be allocating you randomly to one of these groups and will let you know which one you are in after your initial assessments.

We will ask you to complete the survey and assessments now and then again in three months.

The physical assessments you will be invited to take part in are tests of physical function such as walking speed over 4 metres and how many times you can stand from seated in 30 seconds at the start then again in three months. We will minimise the number of tests to reduce burden on your time and you will be given regular breaks.

We would also like to collect a saliva sample from you, once at the beginning of the programme and again at the end. This is to measure levels of stress hormones (cortisol and DHEA), that also relate to physical activity and ageing. We will also ask you what time you got up that day and record the time of day of the sample collection. We will ask you not to eat or drink for one hour before this sample, except water.

You have been invited to participate because you are an adult aged 60+ years living in a care home. This survey is part of a research project being conducted by Professor Anna C. Whittaker and the SPARKLE team at the University of Stirling. You will be given some questions to answer which should take approximately 30 minutes or more to complete. Physical function tests will take 30 minutes to one hour. After the 12-week programme, you may also be invited to a follow-up online interview or small group discussion for up to 1 hour to get your opinions about the programme. Please read through these terms before agreeing to participate below.

Do I have to take part?

No. Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty by pressing the 'Exit' button / closing the browser or telling the researcher helping you that you want to stop. You are free to decline to answer any particular question for any reason – we have included a 'prefer not to say' option, which you are free to use at any point. For the physical function and saliva tests and/or an interview you are free to decline to take part in any of these even if you have taken part in the survey or other assessments.

Are there any potential risks in taking part?

Some of the survey questions ask about loneliness and emotions and may be a little distressing to you as you consider your own experiences. If the questions make you upset, we suggest you talk to your GP

about it if possible, or you could talk to the study Principal Investigator, Prof Anna Whittaker on a.c.whittaker@stir.ac.uk who is a Health Psychologist. Physical function tests and saliva sampling will be conducted by trained researchers and a risk assessment for these has been completed. Physical function tests are immediately stopped any time you are worried about losing your balance and the researcher will be on hand to prevent you falling. We will not ask you to do any tests that your care team think would be unsafe for you.

Are there any benefits in taking part?

The benefits of taking part are helping researchers to better understand how digital resources provided by danceSing Care may help improve mental and physical health. They will also help danceSing Care to evaluate and further develop their programme.

Legal basis for processing personal data

As part of the project, we will be recording personal data relating to you. This will be processed in accordance with the General Data Protection Regulations (GDPR). Under GDPR the legal basis for processing your personal data will be public interest/the official authority of the University. We will also be processing your sensitive/special categories of personal information relating to your health for research purposes in the public interest.

What happens to the data I provide?

Your answers will be completely confidential, we will only be asking your name and contact details so that we can ask you to complete the survey again in 3 months' time, and to invite you to an online interview/discussion. We will store your personal details (name and contact information) separately from the survey data or interview/discussion data and physical function data and saliva sample results. Your saliva sample will have any cells removed on the days of collection (so we will not have your DNA or identifiable data). The sample will then be stored for up to 12 months for analysis and any re-analysis. In storage it will be labelled with an ID number to link to other study data, not with your personal details. After 12 months it will be safely destroyed and only the results of the stress hormone analysis will be saved. The hormone analysis cannot be used for diagnostic purposes. Your data will be stored in password-protected files. Your IP address will not be stored. Your personal data will be kept for 2 years in OneDrive accessible only by the University of Stirling research team for processing and analysis, and then will be securely lodged in our online open access repository DataSTORRE for a minimum of 10 years.

At the end of the survey, you will be asked if you are interested in participating in any University of Stirling future research. We would like to invite you to become part of a future database of older adults (Stirling 1000 Elders) interested in taking part in and learning from relevant ageing research.

Only the research team will have access to personal/sensitive research data. If we use direct quotes from your responses, you will not be identifiable in any publication. Due to the nature of this research, employees at danceSing Care will find the data to be useful in answering their research questions but we will only share anonymised processed and analysed data with them.

Will the research be published?

The research will be published in marketing materials on danceSing Care's website, through social media, and academic presentations and articles. You will be able to access the published results on danceSing Care's website. If you would like these sent to you separately, we will ask for your email address. The University of Stirling is committed to making the outputs of research publicly accessible and supports this commitment through our online open access repository STORRE.

Who is organising and funding the research?

The University of Stirling is sponsoring this research. The ethical approaches of this project have been approved via the University of Stirling NHS, Invasive & Clinical Research (NICR) Ethics Panel.

Your rights

You have the right to request to see a copy of the information we hold about you and to request corrections or deletions of the information that is no longer required. You have the right to withdraw from this project at any time without giving reasons and without consequences to you. You also have the right to object to us processing relevant personal data however, please note that once the data are being analysed and/or results published it may not be possible to remove your data from the study.

Whom do I contact if I have concerns about this study or wish to complain?

If you would like to discuss the research with someone, please contact the Principal Investigator: Professor Anna Whittaker a.c.whittaker@stir.ac.uk.

In case of complaint, please contact the Head of Division Professor Jayne Donaldson jayne.donaldson@stir.ac.uk.

You have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (<https://ico.org.uk/concerns/>). The University's Data Protection Officer is Joanna Morrow, Deputy Secretary. If you have any questions relating to data protection these can be addressed to data.protection@stir.ac.uk in the first instance.

Thank you for your participation.

Electronic Consent

Please select your choice below. Clicking on the "Agree" button indicates that:

- You have read and understood the above information
- You are 18 years of age or older
- You understand you may be randomly allocated to the programme straight away or to the control group who will get the programme 12 weeks later.
- You voluntarily agree to participate

Agree

[added at end of survey]

When your care home is invited to take part in physical function testing and saliva sampling (things like checking your walking speed over 4 metres and how many times you can stand up from a chair in 30 seconds) and your care team think it is safe for you to do this, it would take about 30 minutes to one hour and be with a trained researcher to ensure your safety. This would be at the beginning before the danceSing Care programme starts and again at the end. 12-weeks later. Are you willing to take part in physical function testing?

Yes . No .

We will check this with you again before doing any testing and you are free to change your mind about whether you want to take part in this or not.